

## FOR IMMEDIATE RELEASE

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## SENATE HEALTH AND WELFARE COMMITTEE SUPPORTS SENATOR HEWITT'S LEGISLATION URGING LOUISIANA DEPARTMENT OF HEALTH TO ADD SPINAL MUSCULAR ATROPHY (SMA) TO THE NEWBORN SCREENING PANEL

At the request of State Senator Sharon Hewitt, members of the Senate Health and Welfare committee unanimously approved Senate Concurrent Resolution 16 urging the Louisiana Department of Health to add Spinal Muscular Atrophy (SMA) to the newborn screening panel. SMA is a progressive neurodegenerative disease that affects motor nerve cells in the spinal cord, diminishing all physical strength, impeding the ability to walk, swallow and in severe cases, breath.

"SMA is the leading genetic cause of death for infants today," said Senator Hewitt. "This doesn't have to be the case. Early detection of the disorder allows for expedited treatment that can save a child's life."

At its hearing, members of the Senate Health and Welfare committee heard emotional testimony from the parents of several children suffering from SMA, who had traveled to the Capitol from Mandeville, Prairieville, Ponchatoula, Lafayette, New Iberia, and Abbeville, LA. Their testimony demonstrated that with early detection comes the opportunity to effectively treat the child and change the course of their life.

"There are currently 24 other named diseases included on the newborn screening panel in Louisiana. Seven other states are already testing newborns for SMA at a cost of pennies on the dollar, which pales in comparison to the high medical costs and education costs for children that did not receive the benefit of early detection and treatment. For those families already living with SMA, this is an easy decision," added Senator Hewitt.

SCR 16 now moves to the full Senate and then to the House of Representatives for approval. To view SCR 16 and Senator Hewitt's other bills, please visit <a href="www.legis.la.gov">www.legis.la.gov</a>. More information on SMA can be found at <a href="www.curesma.org">www.curesma.org</a>.



From left to right: (back row) Sadie Leger, Krista Scurria, Senator Hewitt, Bryan Burleson, Kelly Hargroder, Casie Callais, and Brandon Callais; (middle row) Misti Turner, Crystal Menard and daughter, Allori, Jordan Turner, and Brittany Cotogno Melara; (bottom row) Anna Rose Scurria, Joshua Scurria, and Trevor Cotogno.



Senator Hewitt and Casie and Brandon Callais testify before the Senate Health and Welfare Committee on April 15, 2019.

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